

9

STORIES OF CHANGED LIVES

*what's* | possible

- new experiences
- more choices
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- individualized support
- dedicated staff
- peace of mind
- freedom and dignity
- lifelong support
- safe and happy

*what's*

# NINE STORIES OF CHANGED LIVES

Rosewood Center, a residential facility for people with intellectual and developmental disabilities, opened near Baltimore in 1888 — and closed 121 years later in 2009. At one time, over 3,000 people lived there.

Services evolved over those many years, as did attitudes and beliefs about how best to support people with significant disabilities, making

possible

it possible for Rosewood's residents to transition to the community. The last person moved out on May 22, 2009.

"What's Possible" tells the stories of nine people who now call the community home after living at Rosewood for decades. Their stories, representative of many others that couldn't fit in these pages, show what is possible when people are given new opportunities and the community supports they need. Despite initial concerns and sometimes opposition, their families were happily surprised.

We listened to these nine people, and their family members and friends, talk about how life in the community differs from life at Rosewood. They opened up their lives so more of us might understand what community living looks like for people with a variety of significant disabilities. These are their stories.



*new experiences*

# Stephen

*"I think about Stevie and how well he's done in the community..."*

— STEPHEN'S MOTHER

**FIFTY-TWO YEARS LATER,** Shirley still remembers the day she brought her five-year-old son, Stephen, to live at Rosewood. She was overwhelmed by the sight of all the children there. A small boy ran over and threw his arms around her legs. "It was heartbreaking to leave Stevie there, but I believed it was the right thing to do," she explains now.

Her pediatrician had told her that because of his disabilities, Stephen would be better off living with other people like him.

Stephen lived at Rosewood for nearly 50 years. Loud noises would agitate him, and he'd lash out, biting himself and others. "Looking back, Rosewood was not the best place for this, because it was crowded and noisy," says Shirley, who drove four hours each way to visit her son every six weeks.

"I never saw these fits of violence," Shirley adds. "I would hear about them." There were broken bones and choking incidents. "Stevie loves food, but he didn't know how to eat in bites," Shirley recalls. "I used to bring him cookies but I'd feed him one crumble at a time."

Afraid for his safety, Shirley was resistant to the idea of community living for Stephen.

But in May 2009, when Stephen moved into a house in Talbot County with a roommate and support staff, Shirley was pleasantly surprised. She likes his new home, and he made the

transition smoothly. "He has someone with him 24 hours a day, so he's safe," she says. "He loves to watch cooking shows on TV, or sit out on the patio and look and listen." He also attends a day program where he learns skills such as eating and socializing.

Since moving, he has had no incidents of violence. His support staff says that they don't let early signs of agitation escalate, noting, "We offer Stephen choices when possible. And we sing. He loves you to sing to him."

He also loves to go out for rides in the car, and he went to a carnival. Shirley can see him more now that he lives closer to her, and she recently accompanied

Stephen and staff on a trip to the zoo. She was impressed when Stephen was handed an open bag of potato chips, and he ate them himself, one by one.

"When I think about Stevie and how well he's done in the community, I think, 'If only I could have managed him at home, he would have had this life all along,'" she says. It's a deeply bittersweet thought. "That was not possible for our family in that time, without supports."







*more choices*

# Brian

*“Brian has choices now,” Judy says.  
“And more of a life.”*

— BRIAN'S SISTER

**AS A YOUNG BOY, BRIAN HAD A GORGEOUS SMILE** and an easy laugh. “Give me a kiss,” his mom, Alyce, would say, and Brian would lean his head forward to receive her kiss, a gesture that evolved into a gentle tapping of heads to show affection.

Born in 1952 with an untreatable metabolic disorder and autism, Brian moved into Rosewood at age 13. He lived there for the next 43 years. Each month, Alyce made the long drive to visit him and take him out for ice cream.

At Rosewood, Brian retreated into himself. Blind, he also lost the use of his legs and hands, and he was increasingly unresponsive. “Rosewood lacked the right kind of staff and attitude to rehabilitate him,” his sister, Judy, notes. His weight shrank, necessitating a feeding tube.

Alyce continued to visit her son until her death in 2006. She believed the institution was the safest place for Brian, and she opposed its closing. Judy had agreed with her mother for many years, but gradually she saw new possibilities.



In the summer of 2008, Brian moved into a house in Harford County with three housemates and support staff. There, Brian has come to know what Judy calls the “blessing of smallness.” Judy praises a dedicated direct support staff and an overall philosophy for positive changes in Brian’s life.

“The staff excels in their ability to study him,” Judy explains. “They’re learning to read him, to crack the code of Brian.”

This shows in concrete ways. “Brian has choices now,” Judy says, “and more of a life.” He can eat the food he prefers, and he has put on some much needed weight. He can sleep on his own schedule. He can walk around the house a little. He is no longer incontinent by day, thanks to individualized attention from his support staff. Each of these improvements has increased his comfort, says his sister.

He recently took a road trip, went fishing, and took a dip in the ocean for the first time in his life.

While Judy says the family was grateful to his staff at Rosewood, she also points out that “the structure necessary to care for so many people there did not offer Brian what the choices do now.”

“Brian is so much more responsive than when he arrived,” says Ashley, his support staff. “He has begun to smile and reach for my hand, and he does this funny, affectionate head tap with me.”



*family* connections



# Roslyn

*"I love my freedom!" she exclaims in her typically outspoken way. "And I love having my family around me."*

— ROSLYN

**SURROUNDED BY HER FAMILY,** Roslyn celebrates her 59th birthday in the Baltimore County house she shares with a housemate and support staff. Over fried chicken and birthday cake, she talks about how her life in the community compares to her experience of life at Rosewood for 48 years.

"I love my freedom!" she exclaims in her typically outspoken way. "And I love having my family around me."

Roslyn describes her newfound freedom to choose when she can watch Roadrunner cartoons or listen to soul music, how to decorate her room, and where to go on weekends. While the Dollar Store and the park are her favorite places to go, a ride in the car to look at the lights at night also makes her happy. She likes that family members are welcome anytime to keep her company. Several relatives were there for her birthday, including her sister Ida, who lives close by and visits every day. Most emphatically, Roslyn states, "The food is better here!"



Ida says, "Home cooking — choosing what and when she wants to eat — is a huge improvement for Roslyn over institutional meals. Little things like that, that you and I take for granted, make a big difference."

The decision to have Roslyn move into Rosewood at the age of eight was traumatic for her family, who always saw her as "just Roslyn — maybe a little different but nothing wrong with her," Ida says in a soft voice. "She was our sister, and we were close and protective of her always."

But behavioral problems emerged at school due to bipolar issues and an intellectual disability, and Roslyn was not allowed to stay enrolled. "Rosewood was our best option at that time," recalls Ida. Still, the family tried to stay close, making the long trip to bring Roslyn home on weekends and holidays.

How does her family feel about the change now? Ida says that, after nearly five decades of relying on the institution, "The news that Rosewood would close was devastating. But it ended up being one of the best things that ever happened to Roslyn, and to us."



*individualized support*

# Joanne

*“The support staff...ask, ‘what would be good for Joanne?’ and they incorporate the things she likes into her home and community experience.”*

— JOANNE’S SISTER

## JOANNE LIVED AT ROSEWOOD FROM THE

**AGE OF FIVE,** until she turned 54. Her sisters, Olivia and Jeanette, remember how their mother would braid their gentle sister’s hair. Joanne was slow to develop and never learned to talk, and she needed constant supervision.

“Joanne was too gentle for Rosewood. She didn’t like noise, and we felt she was frightened there,” her sisters recall quietly. “She was bothered by the lack of privacy, and she always had to watch her back. She loved to go with us for rides in the car, and she wanted to stay with us. It was heartbreaking every time we had to leave her again.” At Rosewood, Joanne would hide in the bathroom to have time alone. “We stopped giving her clothes and things, because they seemed to get lost.”

The family was grateful for the care Joanne received at Rosewood, and they also wished it could have been better. Over the years, they considered community living for their sister, but they were afraid to experiment with something unknown. “We were naive about how community living works,” says Olivia. “We worried that we might make the wrong decision. What if the staff didn’t show up in bad weather? It felt like such a great responsibility.”

Finally, after 49 years, they had no choice. When Rosewood closed, Olivia and Jeanette looked for three things for Joanne’s new home: a nice neighborhood in the country; low turnover of staff; and a clean, well-kept house.

Joanne and her sisters are happy with her current home in Harford County.

“The support staff are with her all the way,” says Olivia. “I wish I had understood that before. They ask, ‘what would be good for Joanne?’ and they incorporate the things she likes into her home and community experience.” Joanne enjoys going out to the park and the library. She also likes the freedom to walk about her home and yard, listen to music or watch TV, and be quiet in her own room when she chooses. Her housemates are well matched, and they travel together to their day program.

Concerned during the heavy snows of winter 2010, Olivia dropped by to check on her sister. Joanne was safe at home with her housemates and support staff, listening to music and watching the snow fall outside the window.

“She has peace now,” says Olivia.

Jeanette chimes in, “That’s what everyone wants for their family.”







*dedicated* staff

# Guy

*The support staff studied him round-the-clock, asking, “What is he not getting that he needs?”*

## **FROM THE AGE OF SIX, ROSEWOOD WAS THE ONLY HOME GUY KNEW FOR 52 YEARS.**

Born medically fragile and with an intellectual disability, Guy never developed speech. But he impressed Joan — who worked as a supervisor in his day program — with his strong will and resiliency. “He compensates for his disabilities with a great spirit,” Joan says.

She remembers how he played with little toy cars in a corner. But his behavior escalated to violence when his needs weren’t met. Joan recalls, “Others said, ‘Guy is never satisfied. No matter what you give him, he wants more.’ I wondered, ‘What is it he needs?’”

Joan became his friend and advocate: “I noticed he craved special attention and I tried to give him more. I think by recognizing a person’s need for individualized attention, you can calm them.” She noticed his needs were simple: food or attention. “But at Rosewood, there was little time for individual attention.”

Joan worked at Rosewood for 20 years, and she felt it was a good facility in many ways. Guy was one of the last to leave, and Joan worried about his transition. “Even if your environment isn’t the most wonderful, you’re comfortable with what you are most used to,” she says. “So it was a huge adjustment for Guy to leave Rosewood.” She felt sad to see how little he



had to pack after 52 years — just a change of clothes. Guy moved into a house with support staff in Baltimore County.

Soon after, Guy was hospitalized with pneumonia, and doctors expected him to die. He came home under hospice care, and Joan and his caregivers tried to increase his level of

comfort. The support staff studied him round-the-clock, asking, “What is he not getting that he needs?”

A medication change and smaller, more frequent meals, including middle-of-the-night snacks, brought a big improvement in his health, and he has blossomed ever since.

He calmed down and began gaining weight. Taken off hospice care, he worked on walking through physical therapy. And his day program was built around his needs.

As staff got to know him, they learned the different nonverbal ways he communicates his wants and needs, so they could better meet them.

Guy enjoys his life now. He has his own bedroom with clothes and possessions neatly organized. He has gone out to a baseball game and the National Aquarium. Joan lives near Guy, and they like to go to a diner to hear 1950s rock and eat ice cream sundaes. The waitresses know him and greet him, and he laughs. “It’s good to see him enjoy his life in the community,” says Joan. “This means so much to me.”





peace *of* mind

# Donna

*"I feel confident in my sister's care now.  
I'm happier and I sleep better at night."*

— DONNA'S SISTER

**THE FIRST OF EIGHT CHILDREN,** Donna was born with a seizure disorder and multiple disabilities. As a young child, she required so many medical tests and surgeries that her siblings were often sent to stay with relatives. Her sister, Shelia, recalls watching their parents struggle to take care of Donna.

At age seven, Donna went to live at Rosewood. She would stay there for the next 46 years. Shelia would become her most loyal friend and protector.

Finding visits to Rosewood unbearable, their mother stopped going to see Donna. Shelia continued to go with their father, who she says never could accept that Donna was born with significant disabilities. Their parents later divorced.

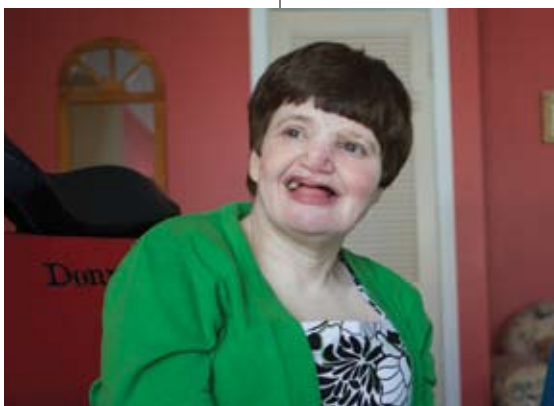
Shelia never felt comfortable visiting the institution. To her, it seemed more like a hospital than a place to live. Still, "it was the only life Donna knew. I couldn't imagine her in a house — I worried would the staff show up?" The family agreed that Donna was best off at Rosewood.

But, hoping for a different life for her sister, Shelia later began to consider other places for her to live. In 2008, Donna moved into a house in Baltimore County with three housemates and support staff. Shelia has a long list of things she loves about her sister's new life.

Donna's house looks like a home, with curtains and bedspreads and personal pictures on the wall. She gets a bath every day, and never misses a meal. Besides attending her day program, she has gone out to church, the mall, the movies, and the circus. Shelia lives nearby, and is welcome anytime. She feels more informed and involved in Donna's life now. And Donna, says her support staff, "has really lit up since she moved here."

"At Rosewood, it was a different person on the phone each time," Shelia says. "Now I can call anytime and talk to her support person who knows her. I love the ladies who care for her...they are right on top of everything."

Shelia wants others to know: "I was afraid at first, but change is good. I feel confident in my sister's care now. I'm happier and I sleep better at night."





freedom *and* dignity

# John

*“John now has a sense of freedom that Rosewood couldn’t offer.”*

— JOHN’S NEPHEW

## **JOHN LIVED AT ROSEWOOD FOR 67 YEARS,**

from ages 13 to 80. As a child, he was called “Sonny” by his three sisters who helped their mother care for him at home until this became too difficult. Mobile but non-verbal, John has significant intellectual disabilities.

His transition to institutional living was wrenching for his mother. Still, his family felt it was the right place for him for almost seven decades. His parents scheduled regular visits during their lifetime, and his father dressed up as Santa Claus for all the children there at Christmastime.

John’s family — which includes his nephew, Lee, who is now John’s guardian — was adamantly opposed to the closing of Rosewood. They feared John would find it too difficult to adjust to a new setting, after so many years of institutional life. But in 2008, as a result of the decision to close Rosewood, John moved into a house in Howard County with a housemate and support staff. Now 81 and healthy, John is doing fine.

Looking back, Lee says “We had concerns that did not materialize. He made the transition beautifully. I don’t think he skipped a beat. His home is warm, comfortable and decorated nicely; I wouldn’t mind living there myself.” And although the family was satisfied with the care John received at Rosewood, Lee says that the people now working with John seem more attentive — and they know him better, more in-depth.

John is always clean shaven and well dressed, notes Lee, who adds that John’s food is freshly and at times individually prepared, allowing him to thrive in his new surroundings.

“I loved Rosewood,” says Lee, “but this supersedes the comforts there.” And although John needs assistance with all tasks of daily living, “He is not confined to the house,” Lee points out. “John now has a sense of freedom that Rosewood couldn’t offer. He has gone on a camping trip and stayed in a cabin in the woods, and he has regular evening outings.”

John’s family can stop by anytime to visit him, and they feel at home. John’s sister, now 88 and using a wheelchair, tells Lee, “Let’s go see Sonny one more time.” She sits with John in his living room, and they hold hands. She remembers their childhood when she was often in charge of her little brother. Together again, their special bond remains strong.







*lifelong support*



# Mary

*"I know Mary's OK. Everything will be all right."*

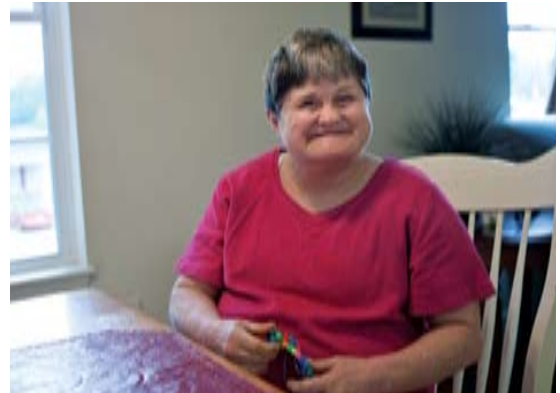
— MARY'S MOTHER

**FIFTY-SEVEN YEARS AGO,** Margaret and John learned that their only child, Mary, would never talk. The doctor said the two-year-old's brain had stopped growing. "I cried all the way home," Margaret recalls. Beneath the sorrow was a bigger feeling: "We love her dearly, and she has always known that she is loved. We consider her a gift from God, and keeping her home with us was very important to her father and me. We love to be with her. And Mary knows what love is."

But by the time Mary was 10, her parents were exhausted from caring for her alone. "We weren't getting proper sleep," says Margaret. With no in-home support available at that time, Mary went to live at Rosewood for the constant care she needed.

"We were grateful to have that help," Margaret explains. "Everyone at Rosewood worked well with her." Once a week for decades, both parents travelled all day by bus to visit their daughter. "It was a long trip, but worth it," Margaret says now. As they got older, however, their health deteriorated and they could no longer manage the trip.

Yet Margaret and John fought Mary leaving Rosewood to live in the community. They feared for their daughter's safety out in the world. They worried about supervision and protection. They also wondered about lasting and stable funding.



Now Mary lives in her own apartment in Carroll County, with 24/7 support staff. Her parents are delighted. Margaret says, "It was a big change, but it went far better than we thought. We were pleasantly surprised and grateful for what's going on in Mary's life."

Mary gets the attention she needs, and she loves to go out each day. Her support staff takes her for drives in the car, picnics in the park, and walks in the mall. Thanks to the attentiveness of her staff, Mary can use the bathroom now and no longer has to spend the day or night in diapers. "It seems like nothing's impossible," says Margaret.

Most important to her parents, who are in their 80's, Mary lives close by now, and she can visit them regularly. Margaret smiles and says, "Thanks to her support staff, she comes to us to eat breakfast or dinner a few times a week." She pauses before adding, "I know Mary's OK. Everything will be all right."



safe *and* happy

# Clifton

*"They really do pay attention to him.  
He's safe and happy."*

— CLIFTON'S SISTER

**ASK CLIFTON** if he'd like to return to Rosewood, his home for 20 years, and he'll tell you emphatically "No! I like my life here." Here is a house he shares with a housemate and support staff in Baltimore City.

That's an amazing comment coming from a 45-year-old man who has mostly "liked to be wherever he's not," as his uncle affectionately explains. Clifton's sister describes him as lovable, a man with an electric personality. But an intellectual disability and desire to wander made it hard to keep him safe while living with his family. Both brother and sister were raised by their grandmother.

As a teenager, Clifton watched Superman on TV and then jumped out a third-floor window thinking he could fly. Instead, his injuries put him in a body cast for six months. He defied doctors' predictions when he walked again.

He moved in with his uncle, who struggled to keep him safe. But despite all precautions, Clifton would find a key in the night to unlock the door, and he once disappeared for 24 hours. Later, he was found injured and covered with eggs that boys had thrown at him.

"Look, you let me get out," he told his worried uncle.

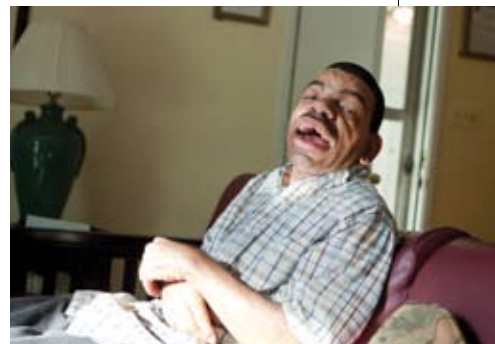
Finally, he went to live at Rosewood. "Even there, he got out a few times," his uncle sighs.

Whenever it was time to return to Rosewood after visiting his family, Clifton resisted. "That made me sad," recalls his uncle.

However, "it was working out OK at Rosewood," his sister adds. "We worried about the closure and what that would mean for Clifton." His smooth transition to community living put her mind to rest. "They really do pay attention to him," she says, "He's safe and happy. And he and the support staff stay in touch with me."

There are lots of reasons Clifton prefers his life in the community. He loves to go to the park, look around, talk and make friends.

He was thrilled by a trip to Las Vegas. He enjoys bowling and eating pancakes in a restaurant. At



home, he makes choices about what to eat, and whether to turn on the TV or dance to James Brown songs. He has arranged his own room with labels on his drawers to organize his things. And he makes phone calls to his family and girlfriends whenever he wants.

Now after visits with his family, he happily leaves for his house in the city, calling out, "See you, bye!"

"He's eager to go home," says his uncle with a smile.

# *what's* possible

## LEARN MORE:

**Years at Rosewood:** Many people who successfully transitioned to the community lived at Rosewood for decades — some for more than 60 years.

**Keeping families connected:** To support family connections, efforts were made to move people close to their families when desired. Two people moved to other states where they receive community services near their sisters. Another former Rosewood resident now receives supports in Israel where his mother resides.

**Choice of service provider:** Rosewood residents and their families chose their new community service providers; with few exceptions they had several options.

**Living situations:** Most people who moved from Rosewood now live with no more than two roommates — some chose roommates with whom they already had friendships.

**Planning:** A person-centered plan was developed for each individual to guide their transition to the community. It was designed to support each person's needs, wishes, and preferences.

**Mentoring:** Peer-to-peer mentoring and support was available to Rosewood residents to provide a personal connection to another individual with a disability who already lived in the community.

**Supporting families:** Family-to-family support was offered to assist families through the transition process and to help them feel informed and confident in the choices they made.

**Quality of Life:** A quality of life survey was implemented to study the impact of the move on people's lives. The survey was initiated while people were still living at Rosewood and will be repeated in the community.

**Monitoring:** Everyone who transitioned to the community was visited by a Resource Coordinator 30, 60, 90, and 180 days following their move from Rosewood to ensure they and their families were satisfied with their supports and services and to resolve any concerns.

**Oversight:** The state maintained strong oversight during and after each person's transition to the community, including ongoing measures to ensure health and safety and quality of life.

**Impact:** With new supports in place in the community, notable changes occurred in people's lives.

THANK YOU TO  
THE INDIVIDUALS  
AND FAMILIES  
WHO GENEROUSLY  
OPENED UP  
THEIR LIVES AND  
SHARED THEIR  
STORIES.

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*Working for  
communities that include  
and support everyone*



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